

CASES

Seeking The Beauty Of Stillness

By ANNETTE RACOND

Certain moments in my life are like sharply focused snapshots that never fade. I was in my flannel pajamas watching TV in my parents' bedroom in Douglaston, N.Y., the day Neil Armstrong stepped onto the moon. More than a decade later, when news broke of John Lennon's death, I was cramming for a test in my dorm room at Boston University.

On April 1, 2004, I had another such moment: My mother called to tell me that Jeff Matovic, a 31-year-old husband and father from Lyndhurst, Ohio, had become the first person with Tourette's syndrome in the United States to be treated with deep brain stimulation. His doctors say the procedure has so far relieved Mr. Matovic of the tics that came with his disorder. He is no longer a constant prisoner to the abrupt and repetitive muscle movements and vocalizations that made his life unbearable. Mr. Matovic can now experience the beauty of stillness.

As a fellow Tourette's syndrome sufferer, Mr. Matovic's story has given me hope that maybe I, too, can be freed from my tics, twitches, bobs, nods, grunts, squirms, hiccups and jolting motions. Even though I exhibited symptoms of Tourette's syndrome at age 6, the disorder was not diagnosed until I was 28.

Before that, numerous doctors had assured my parents and me that I would "outgrow" my tics. Over the years, I was told by members of the medical world to engage in more "daring" sex, to surround myself with plant life and to try "tribal therapy," removing my clothes and letting my inner child break out into a scream.

After an accurate diagnosis was finally made by doctors at New York-Presbyterian Medical Center, I was told there was no cure in sight. The best I could hope for was the minimal relief provided by drool-promoting drugs.

Not only is it difficult to live with the symptoms of Tourette's syndrome, it is even more difficult to live with the stigma. Coprolalia, involuntary swearing and cursing that has its basis in neurobiology, is the main aspect of Tourette's portrayed in the media. Yet just a small minority of people have coprolalia, and I am not among them.

Television shows like "Law and Order" present an unrealistic and frightful view of Tourette's. Because inaccurate information is so widespread, potential em-

A discovery on Tourette's syndrome brings hope.

ployers are often afraid I might shout obscenities at their clients, or at them.

Despite these obstacles, I have forged ahead. At 44, I have spent a good portion of my life learning to accept my circumstances and to discover what I can do. I can run. I can write. I can be funny. I can also learn: I earned a master's degree from New York University.

My family and friends supplied encouragement when I felt defeated. "They'll probably find a cure in the process of looking for something else," I was often told, but never really believed.

Witnessing a medical breakthrough of this magnitude in my lifetime was highly unlikely. Mr. Matovic urged his doctors at the University Hospitals of Cleveland to use a deep brain stimulation technique previously reserved in the United States for treating the shaking associated with Parkinson's disease. The procedure involves implanting electrodes into the part of the brain involved in controlling movements, then attaching these electrodes to a pacemaker using wires.

The results were evident sooner than anyone had anticipated, shocking even the doctors.

"This is what we refer to as a jaw-dropping moment," Mr. Matovic's neurologist, Dr. Brian Maddux, told "Good Morning America" on April 1. Tourette's syndrome, a so-called orphan disease, had finally made international headlines.

Orphan diseases, commonly defined in the United States as conditions that affect fewer than 200,000 people, do not normally generate the same attention, or financing that more mainstream diseases do. Celebrities rarely speak on behalf of them. The real medical muscle is primarily focused elsewhere — on new techniques of cosmetic surgery, for example.

But while acquaintances of mine are getting the fat sucked out of their thighs and put into their lips, I can't escape the wrath of these relentless tics. Finally, someone took a chance to help one man overcome Tourette's syndrome, and I'm optimistic this will lead to many more recoveries.

My mother's phone call opened up the possibility of a new way of life for me, a life where I can be still in the still of the night. Some Americans thought the coverage of Neil Armstrong's walking on the moon was a hoax. Others did not believe that John Lennon was shot. Imagine their reactions if these events occurred on April Fool's Day.

But on that very day, I began believing in the power of medicine.